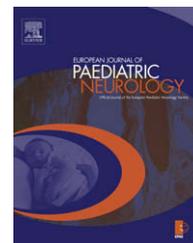




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Original clinical historical contribution: Stuart Green Vignettes

Stuart Green's Vignettes 19 and 20

1. Some parents are never satisfied

A child with a complex developmental problem, cardiac and bowel disease was referred to me by the family's GP who wanted a further opinion. The parents were older. The couple was almost like the traditional seaside postcard couple with a very large matronly woman and diminutive husband. She did all the talking. When I examined the child I realised that most things that needed to be done had been done but I said to them that since cardiac surgery had come a long way in the last five years it might be worth reviewing the child's cardiac problems to see if any further surgery could be done. That was immediately rejected. "We were told seven years ago that an operation could kill our child. Is that what you want to do?" "No" I said, "I was trying to offer some further help. What if we brought in a gastroenterologist to see if some new procedures could be instituted?" "No". That wasn't satisfactory either. "What do you actually want?" I asked. "We would like a prescription (on the Health Service) for non-biological washing powder for our child's napkins and clothes because he is very allergic and we would like some phosphate enemas to help his constipation". I was astonished. "Your GP can give you phosphate enemas on prescription and you can buy non-biological washing powder at any supermarket." "No" they insisted "We want it from your prescription". I said "you have come 40 miles to see me and is that all you want – can't you get this locally?" For the first time the husband spoke and said "No, I'm afraid we can't. We have fallen out with our family doctor and we have fallen out with the local consultants and we can't proceed any further, so we thought we would come and see you". I did not feel pleased as a paediatric neurologist in a tertiary centre to be used as a grocery boy and sympathised with my colleagues with whom the parents had fallen out.

2. Even parents can be rude

When people are distressed – and it is only logical that they can be – they are sometimes extremely rude. We had a child on the ward of about 7 or 8 who had very difficult epilepsy. The parents wanted a) the epilepsy to be controlled and b) the child to be educated at a special private school which taught children with learning

difficulties and epilepsy at the cost of the State system (this is possible in English law in rare circumstances but difficult). We were on the weekly morning round and I could see that one of my Junior colleagues, a paediatric neurologist of sound knowledge and competence in epilepsy, was beginning to get into difficulties with the parents and they were arguing every step of the way. As half an hour passed and the team began to look at each other I (politely) intervened and I said "I realise things are a bit difficult. Perhaps we could have a talk about this later on to-day." I thought this would diffuse the situation. I met the couple about 4.30 pm to see if I could in any way throw some light on the subject or be of some help. I had the notes and looked at them and started off by asking the parents how frequent the seizures were. They said this was an irrelevancy and quoted a leading author on epilepsy who had talked about quality of life rather than frequency of seizures. The conversation went from bad to worse. Every suggestion of any change was negated because of side effect. Any suggestion of possibilities for education other than the exact one they wanted was dismissed out of hand. After an hour and a half of this I said "I am sorry we have not got any further. I tried to intervene to help because I do have some experience in this area but (it was now 6 pm) I will have to stop now as I have to go and pick up my son from school". That was a fatal mistake. I was greeted with the following: "It's all very well for you having a normal son in school, you have no idea what it is like having a handicapped child. The problem is that nobody ever has any time to talk to us!"

Having just given them an hour and a half of my time I was to say the least a little distressed by this. That evening I was called at 1 am in the morning because the child had a seizure and the parents were upset. By the time I came in fortunately the child was sleeping peacefully and appropriate medication had been given. There wasn't a word of thanks and when I said that I was sorry John had had a long seizure the Mother said "No you're not, you don't really care. You are just saying it for the sake of the rest of the team." At that time I had been a paediatric neurologist for over ten years but I felt I still had a long way to go.

Comment: "When parents are distressed – and it is only logical that they can be – they are sometimes – extremely rude".

We will forgive Stuart for the apparently poorly chosen word “logical” in this context, although he may have used it as a short-cut for “it can be more than understandable and even appropriate to let out negative emotions (be rude) when faced with intolerable and intense repeated frustrations. Especially, when they are grafted on the chronic suffering and guilt they do have for their children. Recurrent uncontrolled seizures are certainly one of the most frequent example we encounter of this situation. It is unusual for child neurologists to expose our own feelings of helplessness, contradictory emotions that can assault us in such situations, when we are tacitly and by education expected to be cool and understanding and forget such happenings.

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